A cross sectional study of family caregiver burden and psychological distress linked to frailty and functional dependency of a relative with advanced dementia

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Abstract

Psychological health of caregivers of people with dementia is a major public concern. This study sought to determine the relationship between caregiver burden, psychological distress, frailty and functional dependency of a relative with advanced dementia. Persons with dementia and their caregivers (102 dyads) participated in this Portuguese community based cross sectional study. Data was collected using the Clinical Dementia Rating Scale, a sociodemographic questionnaire, the Zarit Burden Interview, the Brief Symptoms Inventory and the Edmonton Frail Scale. Alzheimer's disease was the most common type of dementia among the recipients of care, who showed moderate (42.2%) to severe (52.9%) dementia. Among them 35.3% exhibited moderate and 45.1% severe frailty. Family caregivers reported moderate (76.5%) to severe burden (18.6%). Psychological distress was very high among family caregivers. Results show that people with dementia exhibited moderate (35.3%) or severe frailty (45.1%) and that a severe frailty was found in people with moderate dementia. A one-way ANOVA was conducted between the Global Severity Index and some sociodemographic variables. ANOVA reached $p < .01$ for employment status of the caregiver, assistance and professional support, and psychiatric history; $p=0.01$ for caregiver age and years of caregiving. Although caregivers reported benefit from the supportive approach offered by the multidisciplinary home care team, high levels of distress and associated burden were found, which might decrease their capacity to care for the person with dementia and their own health and well-being.

Keywords: advanced dementia, caregiver, caregiver burden, distress, frailty

Introduction

Global ageing coupled with the rising number of people with dementia is a major global public health challenge, placing strain on both health and social care services and family caring (Muders et al., 2015). It is estimated that 47.47 million people worldwide are living with dementia, and this will increase reaching 75.63 million in 2030 and 135.46 million in 2050 (WHO, 2015).

Family caregivers occupy a central position in decision making about the person with advanced dementia, particularly during the later stages of the illness (Gillespie, Mullan, & Harrison, 2014; Sadak et al., 2017). A feature of dementia care policy in many countries is to enable and sustain family caring within the family home for as long as possible. Unfortunately, the reality of experiences for many is that the lived experience of advanced dementia and family caring falls short of the policy rhetoric (Tolson et al., 2016).

Caregiving typically involves attending to another person's health and care needs and includes assistance with one or more activities of daily living. It involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting. It is also important to recognise that caring has many rewards, which are amplified through reciprocity in the caring relationships (Van der Steen et al., 2014).

Lack of family caregiver information and training to care has been shown to escalate difficulties and the demands of caring are often coupled with carer's loss of their own social networks, leisure pursuits and for some paid work (Arango Lasprilla et al., 2009). Many studies report carer overload and development of psychopathological disorders and loss of well-being (Dawood, 2016; Gitlin & Hodgson, 2016; Terum et al., 2017).

Dementia is a chronic syndrome arising from illnesses such as Alzheimer's disease. It is a progressive condition in which there is a decline in cognitive function beyond what might be expected from normal ageing; dementia affects memory, thinking, orientation,

comprehension, calculation, learning capacity, language, and judgement. The deterioration in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, motivation or functional capacity (WHO, 2017).

The trajectory, progression of symptoms and prognosis of dementia may not be linear; depend on the interplay of several factors (Crowther, 2015). Although it is recognised that the experience of dementia is unique to the individual, there are patterns of physical decline and impairment of communication in many; some experience severe cognitive impairment ahead of physical decline. The occurrence of frailty is mainly a state of vulnerability resulting from comorbidities and the overall decline in organ functions.

The staging of dementia severity is important for clinical and research purposes. Commonly used stages are mild, moderate and severe; a recent European project Palliare, however argued for reconsideration proposing mild, moderate and advanced dementia (Hanson et al, 2016). Advanced dementia being a period associated with living the best life possible with later stage dementia rather than solely focussing on severe dementia, death and dying (Hanson et al., 2016; Tolson et al., 2016). This extended palliative care phase can extend from months to years.

The Palliare project identified support for family caring as a key component of best practice placing emphasis on proactive support to sustain relationships between the person with advanced dementia, family and friends (Holmerova et al., 2016).

As dementia advances, increasing levels of dependency can become difficult for families to manage at home. Unfortunately, for some families, what has been described as caregiver burden can be a factor in multiple hospital admissions, and a factor in the admission to a long-term care facility such as a nursing home (Van der Steen et al., 2014).

There is evidence that caring for people with dementia can interfere with the caregivers psychological health and morbidity - depression, neuroticism and high levels of

burden (Campbell et al., 2008; Irwin et al., 2013; Peng & Chang, 2013). Studies consistently report higher rates of anxiety and depression among family caregivers of people with dementia than comparable figures for family caregivers of relatives with other degenerative conditions (Irwin et al., 2013; Bekhet, 2015; Muders et al., 2015).

To sustain family caring it is important to more fully understand the experience of caring for a relative with advanced dementia and to understand the impact of these on carer's psychological symptoms, and on perception of burden.

The study reported in this paper is part of the major DRIVE-C Project [http://www.esenf.pt/pt/i-d/projetos-internacionais/drive-c/] that is concerned with improving community care within the Porto District (North of Portugal).

The main purpose of this paper is to explore the impact of frailty and functional dependency of people with advanced dementia upon their caring relative's psychological health. The following hypotheses were formulated:

(1) Family caregivers experience significant psychological distress when caring for people with dementia;

(2) There is an association between the Global Severity Index (GSI) and the number of years of the caring process and benefits from professional support;

(3) There is a positive association between the frailty of people with dementia and the caregiver's Global Severity Index (GSI).

Methods

A community-based cross-sectional study with a non-probabilistic sample was conducted.

Settings and participants

The study was completed over three years (2014 to 2017) in the Porto District of North Portugal. The study sample comprised of 102 caring dyads (204 persons - persons with dementia and family caregivers) selected by practitioners from the home care team (Integrated Community Care Team). A total of 140 caring dyads were invited to participate, 102 met the inclusion criteria which stipulated i) dementia diagnosis by physicians using the CDR (Clinical Dementia Rating); (ii) completed initial clinic assessment by the multidisciplinary team; and (iii) ongoing support at home provided by the local long-term care team.

Local mental health nurses identified potential study participants and supported researchers in the process of data collection. These mental health nurses facilitated contact between the participants and research team. Visits to collect data were scheduled according to the caregivers' availability.

Data collection and analysis

A set of tools were selected to gather data from both the person with dementia and the family caregiver. The sociodemographic questionnaire was used to collect data from the participants (person with dementia and caregiver) and the home context of care. The Brief Symptom Inventory (BSI) (Derrogatis, 1993) was used to evaluate the psychological distress of family caregivers and the Zarit Burden Interview (ZBI) (Zarit et al., 1980) to evaluate the burden on the caregiver. The Edmonton Frail Scale (EFS) (Rolfson et al., 2006) was chosen to assess the frailty of the person with dementia. Findings of the routinely completed Clinical Dementia Rating (CDR) (Hughes et al., 1982) were used as this was collected following a standardised protocol to cognitive assessment, based on the orientations from DGS (Health General Department - 53/2011) and the GEECD - Study Group on Brain Aging and Dementias (2008).

Research tools

The BSI (Derrogatis, 1993) is a 53-item questionnaire that assesses nine dimensions of psychological distress: somatization, obsession-compulsion, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. Wieland et al (2012) state that BSI as a screening instrument for psychopathology. However, in this study, we used BSI to describe psychological distress rather than to provide a measure of mental health disturbances (Payton, 2009), which would require additional assessment.

The BSI includes three indices of global distress: Global Severity Index (GSI), Positive Symptom Distress Index (PSDI), and Positive Symptom Total (PST). The total scale score for the GSI is the mean of all 53 items. It reflects both the number of symptoms and intensity of perceived symptoms. The PST is calculated based on the total count of the number of non-zero responses and reveals the number of symptoms the respondent is experiencing. The PSDI is calculated by summing the values of the items receiving non-zero responses divided by the PST. This last index provides information about the average level of distress the person experience. Derrogatis (1993) argues that the GSI is the scale that is the most sensitive single indicator of distress, because it is the mean of all 53 items. Moreover, people who have values above cut-off points in more than two subscales should receive additional attention and support.

Internal consistency reliability coefficient (Cronbach's alpha) value of BSI was good, with an average rating above 0.7 for the scales (Derrogatis, 1993).

The ZBI (Zarit et al., 1980) is a 22-item survey asking caregivers to respond to several aspects of caregiver burden. The tool uses a 5-point Likert scale ranging from ‘Never’ to ‘Nearly Always’ caregivers were asked to respond to a number of statements relating to the care of the person with dementia. Scores range from 0 to 88 with a higher score indicating a higher level of burden. The scale has a multidimensional structure based on four factors:

caregiving impact, personal relationship, expectations of caregiving and perception of effectiveness.

The Edmonton Frail Scale (EFS) assesses nine domains of frailty in old people (cognition, general health status, functional independence, social support, medication usage, nutrition, mood, continence and functional performance) (Rolfson et al., 2006). Total score varies from 0 to 17. The participants were classified conventionally into categories, and a higher score represents a higher degree of frailty. Severe Frail and non-frail participants were defined according of the EFS score from No frailty (≤5 points), Apparently vulnerable ($6 \leq n \geq 11$ points) and Severe frailty ($12 \leq n \geq 17$) respectively (Rolfson et al, 2006). In this study, our option consisted in making two observations by different researchers and reach a consensus on the item score to be assigned to each dimension.

The CDR, developed by Hughes et al. (1982) is a numeric scale commonly used in dementia diagnosis and staging of dementia severity. The tool has been used widely in the last three decades in the evaluation and staging of dementia. The validity and reliability of the CDR have been demonstrated, including in multicentre studies. A literature review conducted in November 2008 revealed 708 references since 1982 for the CDR, which has been translated into 60 languages (Morris, 1993; Williams, Roe & Morris, 2009).

All of the above instruments have been validated for use with a Portuguese population table below as shown in Table 1.

Table 1. Validation of the instruments to the Portuguese population

Instrument	Authors	Year	Psychometric information
Brief Symptom Inventory (BSI) (Derrogatis, 1993)	Canavarro	1999	• Global Cronbach's **alpha** - 0.97 • Scales Cronbach's **alpha** - 0.71 (psychoticism) to 0.85 (depression) • Reference values to the population: 0.835 for GSI, 26.993 for the PST and 1.561 for the PSDI.
Zarit Burden Interview (ZBI) (Zarit et al., 1980)	Sequeira	2010	• Global Cronbach's **alpha** - 0.93 • Scales Cronbach's **alpha** - 0.79 to 0.92 • The evaluation of burden includes four categories: No burden (<46), Mild to moderate burden (47 – 55) and Severe burden (>56).
Edmonton Frail Scale (EFS) (Rolfson et al., 2006)	Martins et al	2012	• Global Cronbach's **alpha** - 0.97 • Reliability threshold of 0.94 for test-retest reliability (95% confidence interval, 0.90-0.96).
Clinical Dementia Rating (CDR) (Hughes et al., 1982)	Garrett et al	2008	• Global Cronbach's **alpha** - 0.91 • No cut-offs points were used, because people performance is compared with their previous condition.

GSI - Global Severity Index
PSDI - Positive Symptom Distress Index
PST - Positive Symptom Total

Statistical analysis

The data analysis was performed using the statistical program SPSS version 24.0 (Statistical Package for the Social Sciences; SPSS Inc., Chicago, IL), allowing appropriate statistical analysis.

To all univariate tests a 95% confidence interval was considered. The one-way analysis of variance (ANOVA) was used to determine whether there are any statistically significant differences between the means of three or more independent (unrelated) groups; in this study, ANOVA was performed to evaluate whether Global Severity Index (GSI) differs or has differences between a set of variables. The Pearson Correlation was used to analyse the association between the ZBI total score and the Global Severity Index (continuous variables).

Ethical Considerations

Ethical approval was granted from the Institutions' Ethics Committees (Institutional Review Board LHU-33/2014/RS and MLH - 20140204). Participants (family caregivers and people in early or moderate stages of dementia) were asked to sign a consent form after being informed of the content and purpose of the study. In the later stages, dementia affects an individual's capacity to consent (Whitehouse, 2000; Sorrell & Cangelosi, 2009). For individuals who lacked capacity the family caregiver (legal guardian) was approach to provide consent . All participants were reassured that taking part in the study would not interfere with ongoing treatment and care, and that they could withdraw from the study at any time without explanation or redress.

Findings

Demographic data of the participants (person with dementia and the family caregiver (n=102) are shown in Table 2. The majority of people with dementia were women (65.7%) and had a mean age of 80.8 years. Most caregivers were female (88.2%), 74.5% had an educational level of primary education and were married or live in consensual union (77.4%). Caregivers had a mean age of 60.6 years and the range of age was 18 to 87 years. On average, caregivers had been providing care to the persons with dementia for 19.8 months (range: 1-85).

Table 2. Sociodemographic characteristics of the person with dementia and the family caregiver (N= 102)

Variables	Person with Dementia	Family Caregiver
Age (mean)	80.8 (Range 50 – 95) (sd: 7.8)	60.6 (Range 18-87) (sd: 13.9)
Gender		
Male	35 (34.3 %)	12 (11.8 %)
Female	67 (65.7 %)	90 (88.2 %)
Education		
Illiterate	18 (17.6 %)	4 (3.9%)
Primary education (9 years or less)	80 (78.4%)	76 (74.5%)
Some secondary education (10 - 12 years)		4 (3.9%)
Completed secondary education (12 years)	1 (1.0%)	11 (10.8%)
Bachelor degree or more	3 (2.9%)	7 (6.9%)
Marital status		
Single		12 (11.8 %)
Married and / or consensual union		79 (77.4 %)
Widowed		5 (4.9 %)
Divorced		6 (5.9 %)
Employment / Occupation		
Unemployed		17 (16.7 %)
Employed		21 (20.6 %)
Home worker		16 (15.7%)
Retired (age)		25 (24.5 %)
Retired (disability)		18 (17.6 %)
Student		2 (2.0 %)
Other		3 (2.9 %)
Relationship of family caregiver with the person with dementia		
Wife/husband		36 (35.3 %)
Son / daughter		36 (35.3 %)
Son-in-law / daughter-in-law		4 (3.9%)
Brother / sister		4 (3.9%)
Father / mother		7 (6.9 %)
Grandson / granddaughter		3 (2.9 %)
Other		12 (11.8%)
Time of caregiving (months)	Mean: 19.8 (Range: 1-85) sd: 19.5	

Table 3 shows the stage and types of dementia of the patients. The Table indicates that most persons with dementia had severe (52.9%) and moderate (42.2%) dementia. Alzheimer's

disease was the most common type of dementia (41.1%), with 15.7% having a diagnosis of vascular dementia.

Table 3. Stage and types of dementia (N= 102)

Person with Dementia	n (%)
Clinical Dementia Rating (CDR)	
Mild	5 (4.9)
Moderate	43 (42.2)
Severe	54 (52.9)
Types of Dementia	
Alzheimer's disease	42 (41.1)
Vascular dementia	16 (15.7)
Dementia with Lewy bodies	2 (2.0)
Frontotemporal	5 (4.9)
Mixed dementia	5 (4.9)
Other	2 (2.0)
Under study	30 (29.4)

The BSI was used to evaluate psychological distress. Findings are summarized in Table 4. Alpha coefficients of the different sub-scales ranged from 0.62 to 0.80. For seven subscales, coefficient alpha exceeded 0.70, which is considered adequate. For two sub-scales scores were 0.62, but is important to keep in mind that each of these scales has only 4 to 5 items; the number of items in a scale can have a pronounced effect at lower levels of inter item correlation (Peterson, 1994).

The mean values for each BSI subscales are followed by those calculated for the Portuguese population (cut off point) in parentheses. As can be seen, the values obtained in all subscales are higher than the reference values.

The BSI also includes three indices of global distress: Global Severity Index (GSI), Positive Symptom Distress Index (PSDI), and Positive Symptom Total (PST). The GSI measure current or past level of symptomatology and its intensity (it is the mean of all 53

items), the PST the number of reported symptoms, and the PSDI intensity of symptoms respectively.

Concerning the GSI, the cut-off point for clinically significant distress are, according to the test manual, for all dimensions at the T-score of the normative population sample of T = 0.63. The calculated value to GSI is higher than that of the reference value. Considering the cut-off above 1.56 at the PSDI (to the Portuguese population), which indicates emotional disturbance, in general caregivers seem emotionally disturbed, as was expected given the values in all BSI dimensions.

Table 4 also includes the one-way ANOVA results to assess potential differences between the Global Severity Index by a set of nominal-level variable having 2 or more categories. Results reached $p < .05$ at age of the caregiver, years of caregiving and employment status of the caregiver; $p < .001$ in the follow variables: assistance and professional support and psychiatric history. No differences were found in the gender of the caregiver.

Table 4. Brief Symptom Inventory (statistics) (N= 102)

BSI Subscales	**Cronbach Alpha coefficient** [a]	
Somatization	0.79 (0.80)	
Obsession-Compulsion	0.75 (0.77)	
Interpersonal Sensitivity	0.65 (0.76)	
Depression	0.81 (0.73)	
Anxiety	0.77 (0.77)	
Hostility	0.82 (0.76)	
Phobic Anxiety	0.68 (0.62)	
Paranoid Ideation	0.65 (0.72)	
Psychoticism	0.72 (0.62)	
Overall BSI inventory (53 items)	0.95	
Dimensions	**Mean values for the subscales** [a]	
Somatization	2.23 (0.77)	
Obsessive-compulsion	2.7 (1.25)	
Interpersonal Sensitivity	1.98 (0.82)	
Depression	2.49 (0.94)	
Anxiety	2.40 (0.65)	
Hostility	2.08 (1.00)	
Phobic anxiety	1.54 (0.55)	
Paranoid ideation	2.28 (0.96)	
Psychoticism	1.75 (0.62)	
Global Severity Index	2.19 (0.83)	
Positive Symptoms Total	25.96 (26,99)	
Positive Symptoms Distress Index	5.31 (1.56)	
	ANOVA (F)	***p***
Global Severity Index		
Age of the caregiver	1.9	0.01
Gender of the caregiver	0.52	0.98
Employment status of the caregiver	2.13	0 .01
Years of caregiving	2.04	0.01
Assistance and professional support	63.79	< 0.001
Psychiatric history	5.56	<0 .001

[a] Observed values and reference values for the Portuguese average population (Canavarro, 2007)

Table 5 shows the values obtained with the application of the ZBI. The assessment of burden among the caregivers found means higher than the medium value in the four subscales. The categorization of burden revealed 76.5% with mild to moderate burden and 18.6% with severe burden. As the BSI Global Severity Index reflects both the number of

symptoms and intensity of perceived distress, a Pearson product-moment correlation coefficient was computed to assess the relationship between the GSI and the caregivers' reported experiencing burden; there was a positive correlation between the two variables (r = 0.28, n = 102, p = .003).

Table 5. Family caregiver burden (Zarit Burden Inventory) (N= 102)

Dimensions explored using the ZBI	**Mean**	**sd**
Impact of caregiving	35.9	11.9
Interpersonal relation	13.3	5.9
Expectancy from caregiving	13.8	3.5
Perception of self-eficacy	5.4	2.8
Burden categories		
No burden (<46)	5	4.9
Mild to moderate burden (47 – 55)	78	76.5
Severe burden (>56)	19	18.6
Cronbach Alpha coefficient (average)	0.91	
Correlation GSI / Global Burden	Pearson r = 0.28 (p =0 .003)	

GSI - Global Severity Index

Table 6 shows the prevalence of frailty among the 102 participants with dementia. The categorization of frailty revealed 35.3% with moderate frailty and 45.1% with severe frailty. Table 6 shows also a cross-tab to try to understand the simple relation between frailty and the severity of dementia. As can be observed, in rows are indicated the EFS categories and in columns the stages of dementia according to the CDR. It is reported that 74.1% of the people with severe dementia is severe frailty too. Anyway, 11.6% of people with moderate dementia is also experiencing severe frailty.

Table 6. Frailty and stage of dementia (N= 102)

Frailty and stage of dementia				
Edmonton Frail Scale (EFS)	n (%)			
Not frail (0 – 5)	1 (1)			
Vulnerable (6 – 7)	10 (9.8)			
Mild frailty (8 – 9)	9 (8.8)			
Moderate frailty (10 – 11)	36 (35.3)			
Severe frailty (12 – 17)	46 (45.1)			
Correlation (Frailty and GSI)	$r = 0.20$; $p = 0.04$			
	Dementia stage (CDR)			
	Mild	**Moderate**	**Severe**	**Total**
Frailty (EFS)				
Not frail (0 – 5)	1 (20%)	0 (0%)	0 (0%)	1
Vulnerable (6 – 7)	1 (20%)	9 (20.9%)	0 (0%)	10
Mild frailty (8 – 9)	2 (40%)	7 (16.3%)	0 (0%)	9
Moderate frailty (10 – 11)	0 (.0%)	22 (51.2%)	14 (25.9%)	36
Severe frailty (12 – 17)	1 (20%)	5 (11.6%)	40 (74.1%)	46
Total	5 (100%)	43 (100%)	54 (100%)	102 (100%)

CDR - Clinical Dementia Rating Scale
GSI - Global Severity Index

Discussion

Dementia is a chronic, progressive syndrome that causes adversity in the person but also emotional reactions and often dramatic consequences in family caregivers (Kasper et al., 2015).

This study sought to determine the relationship between caregiver burden, psychological distress and frailty and functional dependency of a relative with advanced dementia.

Caring for people with dementia – the context of care

All participants in this study lived in their own homes and were regularly followed up by the local health team and social services. The majority of people with dementia were women (65.7%) and had a mean age of 80.8 years; some of them had 90 years old or above (n=13, 12.7%). Van der Steen et al. (2014) highlight that dementia may be prolonged in time and that severe disability can go on for years. Most caregivers were female, had an educational level of primary education and were married or living with a partner. The gender of the family caregivers was consistent with similar studies (Wolff et al., 2016); the low educational level is a challenge to the health professionals that develop special psychoeducational programs; education can influence the way caregivers view their role (Brodaty & Donkin, 2009). The most common caregiver relationship with the person with dementia was that of spouse; the decision to take care of a close relative with chronic illness is typical within the Portuguese culture (Zunino et al., 2011). Caregivers had a mean age of 60.6 years – the oldest being 87 years, which means that some carers are also likely to be recipients of care themselves for age related conditions. On average, caregivers had been providing care to the persons with dementia for nearly 19.8 months, some for more than 5 years.

Most participants with dementia exhibited severe or moderate dementia. CDR results showed that many who were classified with "moderate" dementia, also exhibited severe frailty. This is not surprising and highlights the importance and practical relevance of the concept of "advanced dementia" as a recognisable stage prior to "severe dementia".

Prevalence of psychological distress on caregivers

The BSI was used to evaluate psychological distress over a 30-day time period prior to the study. As previously stated, caregivers present high values in all the subscales (the calculated values are higher than the cut-off points). One important conclusion is that family

caregivers of this study have high levels of distress. Thus, the first hypothesis was confirmed - family caregivers experience significant psychological distress when caring for people with dementia. Epstein-Lubow et al. (2012) state that psychological symptoms severity (e.g. depression) in caregivers can be associated with the severity of the decline and dependence of the recipient of care. Abdollahpour et al (2012) reveal a higher rate of depression and anxiety among the caregivers of people with dementia as compared to the general population. Psychological distress in family caregivers of people with dementia is often overlooked, which is particularly worrying given the associated risk of development of mental health disorders (Sallim et al., 2015). Moreover, the impact and burden that psychological distress has on everyday life is important at a personal, societal and economic level (Zhu et al., 2015).

The BSI includes three indices of global distress: Global Severity Index (level or intensity of distress), Positive Symptom Distress Index (intensity of symptoms), and Positive Symptom Total (number of reported symptoms). The second hypothesis is also confirmed - there is an association between the Global Severity Index (GSI) and the number of years of the caring process and benefits from professional support. Pereda, Forns & Peró (2007) stated that the BSI dimensions are related to closed constructs that are inter correlated even at the conceptual level. Feast et al. (2016), in the same way, suggest the relationship between behavioural and psychological distress. The PST index was less than the reference for the Portuguese population, which means that for some symptoms the calculated values indicate lower values than those of the reference population. The results of the PSDI indicates emotional disturbance; in other words caregiver participants were emotionally disturbed.

The results obtained with one-way ANOVA, that assesses potential differences between the overall psychological distress levels (GSI) by a set of nominal-level variable having 2 or more categories, are in line with other studies (Endermann, 2005). There are

differences in the following variables on the caregiver: age, employment of the caregiver, assistance and professional support, health surveillance and psychiatric history, and years of caregiving. No differences were found with regard to the gender of the caregiver.

Anxiety and depressive symptoms are common in older people with dementia (Ornstein & Gaugler, 2010; Murray et al., 2012). Caregivers are at increased risk for burden, stress, anxiety, depression, and a variety of other health complications, some of them common to the person with dementia. It is recognised that the intensity of psychological distress identified in this research can led to psychotic morbidity (Vaingankar et al., 2016). This findings aligns with recent evidence which suggests that caring for a relative with dementia can accelerate cognitive decline in caregivers (Dassel, Carr & Vitaliano, 2015; Vitaliano, Ustundag & Borson, 2016),

The assessment of burden among the caregivers showed high means in the four subscales. Effectively, 76.5% show mild to moderate burden, and 18.6% severe burden. There is a possibility of underestimating the consequences of burden, because caregivers look at their role as a duty of love and moral obligation and they also find positive aspects when caring for relatives with dementia (Zarit, 2012; Prorok, Horgan & Seitz 2013; Monin et al., 2015; Roth et al., 2015; Cheng et al., 2016). Burden in caregivers of relatives with dementia is widely reported (Rubin & White-Means, 2009; Gaugler et al., 2010; Mausbach et al., 2014).

As explained all caring dyads within this study were supported by local healthcare teams, which included mental health nurses who systematically evaluated emotional impact and burden on the caregiver. It is unclear how current care provision mitigated the observed the strain of caring, as all participants were in receipt of community care. In general it is believed that community support, including respite options, sustain family caring enabling individuals with dementia to live longer within the family home, arguably at a lower cost than if admitted to a care facility (WHO, 2012; Rattinger et al., 2015; Rattinger et al., 2016).

We decided to investigate if a positive correlation could be found between the Global Severity Index (that reflects both the number of symptoms and intensity of perceived distress) and the caregivers' reported experiencing burden. We found a strong positive correlation between the two variables ($p = .003$). Recent studies have also highlighted this relationship and the risks associated with family caregiving (Liu & Gallagher-Thompson 2009; Goren et al., 2016).

Frailty of people with dementia and the caregiver's psychological distress

Frailty was evaluated among the 102 person with dementia. Arango Lasprilla et al. (2009) and Soto-Rubio, Pérez-Marín & Barreto (2017) found that frailty of people with dementia is positively correlated with caregiver burden and associated with higher levels of depression on the caregiver. The overall frailty in our participants with dementia revealed that 35.3% show moderate and 45.1% severe frailty. Furthermore, findings revealed a positive correlation between frailty of the person with dementia and GSI (number and intensity of symptoms on the caregiver). Thus, the third hypothesis was also confirmed - there is a positive association between the frailty of people with dementia and the caregiver's Global Severity Index (GSI).

The frailty of each of the 102 persons was evaluated and compared with the results obtained from the Barthel Index, through the Lawton and Brody Scale and the various scores that compose the CDR. It was surprising to see the significant proportion of people who had moderate dementia who also exhibited severe frailty. As expected, we found that 74.1% of the people with severe dementia also had severe frailty. However, 11.6% of people with moderate dementia also displayed severe frailty. O'Bryant et al. (2010) and Pialoux, Goyard, & Herme (2013) state that the care provided in the advanced stage of dementia is often fragmented; many patients may die experiencing considerable suffering (Jones et al., 2016) as a result of unrecognized and untreated symptoms. A lack of understanding about dementia has been

identified as a barrier to providing optimal care to people with advanced dementia (Harris, 2006; Penders et al., 2015).

The provision of palliative care or the need for people with dementia to benefit from palliative care were not considered in this study. However, the stages of dementia identified and the severity of frailty suggest that many of these people could benefit from dementia specific palliative care.

Findings from this study emphasize the need to consider a longer period of palliative care, given the clinical and social circumstances in which people with advanced dementia and their family caregivers are living. This need for an "extended period of palliative care" for people with dementia is included in the concept of Dementia Palliare. Dementia Palliare is a positive practice approach to evidence informed interdisciplinary advanced dementia care, which creates a new narrative and importantly reveals the expert knowledge and expert practical know-how that is required to deliver good quality advanced dementia care within long-term care settings (Hanson et al, 2016).

Although caregivers benefit from regular contact and support offered by the multidisciplinary home care team, it is imperative that caring interventions are developed in response to the common experience of pronounced distress and caregiver burden for the many family carers who are caring for relatives with advanced dementia.

Limitations of the Study

In future research with the BSI it would be relevant to test the stability of the distress construct (test-retest reliability) and to explore connections to other distress measures (convergent validity) or external ratings (criterion validity). Religion and spirituality, which may interfere with emotional management, were not considered in this research, despite being important realities for the study population.

Conclusion

In this paper, we investigated the psychological distress reported by caregivers of relatives with dementia. Findings indicate that caregivers experience psychological distress. We have shown that they are emotionally disturbed - high values were found in all BSI subscales and in the GSI.

Many studies evaluating intervention programs have reported psychological distress in carers of relatives people with dementia. The original contribution of this study is that it has integrated an evaluation of family carer distress and burden with the dementia severity and frailty of relative for whom they care. It has revealed a previously unreported high level of frailty in people with both moderate and severe dementia. This draws attention to the enduring and prolonged nature of complex caring responsibilities which fall to many family carers of people with advanced dementia.

This study emphasizes the need to recognise the complexity and challenges of caring for a person with advanced dementia, which may endure for years, and highlights the importance of providing palliative support for both the individual and family throughout this period, rather than compressing this to the final stages of a person's life with severe and end stage dementia (Tolson et al., 2017). There is an urgent need to recognise and provide better palliative care people with advanced dementia and take actions to mitigate the serious health consequences on family caregivers. An extended palliative phase, not limited to people with severe dementia, must be considered, given its importance for appropriate and humanly acceptable care.

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References

Abdollahpour, I., Nedjat, S., Noroozian, M., Salimi, Y., & Majdzadeh, R. (2012). Caregiver Burden and its Determinants among the Family Members of Patients with Dementia in Iran. *Journal of Geriatric Psychiatry and Neurology*, 27(3), 172-180. PMCID: PMC3429801

Arango Lasprilla, J., Moreno, A., Rogers, H., & Francis, K. (2009). The effect of dementia patient's physical, cognitive, and emotional/ behavioral problems on caregiver well-being: findings from a Spanish-speaking sample from Colombia, South America. *American Journal of Alzheimer Disease and Other Dementias*, 24(5), 384-395. http://dx.doi.org/10.1177/153331750934146

Bekhet, A. (2015). Resourcefulness in African American and Caucasian American caregivers of persons with dementia: associations with perceived burden, depression, anxiety, positive cognitions, and psychological well-being. *Perspectives of Psychiatric Care*, 51(4), 285-94. https://doi.org/10.1111/ppc.12095

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neurosciences*, 11(2). 217–228. PMCID: PMC3181916

Campbell, P., Wright, J., Oyebode, J., Job, D., Crome, P., Bentham, P. et al . (2008) Determinants of burden in those who care for someone with dementia. *International Journal Geriatric Psychiatry*. 23, 1078–1085. doi: https://doi.org/10.1002/gps.2071

Canavarro, M. (1999). Psychopathological Symptoms Inventory - BSI [Inventário de Sintomas Psicopatológicos: BSI]. In M. Simões, M. Gonçalves & L. Almeida, L. (Eds.),

Psychological tests and scales in Portugal [Testes e provas psicológicas em Portugal]. Braga. SHO/APPORT, 87-109

Canavarro, M. (2007). Psychopathological Symptoms Inventory: a critical review of studies in Portugal [Inventário de Sintomas Psicopatológicos: uma revisão crítica dos estudos realizados em Portugal]. M. Simões, C. Machado, M. Gonçalves & L. Almeida (Eds.), *Psychological evaluation: validated instruments for the Portuguese population* [Avaliação psicológica: Instrumentos validados para a população Portuguesa]. Coimbra: Quarteto Editora, 3, 305-331

Cheng, S., Mak, E., Lau, R., Ng, N., & Lam, L. (2016). Voices of Alzheimer caregivers on positive aspects of caregiving. *The Gerontologist*, 56, 451–60. http://dx.doi.org/10.1093/geront/gnu118

Crowther, G. (2015). *Palliative care in dementia*. London: Radcliffe Publishing, 10-152

Dassel, K., Carr, D., & Vitaliano, P. (2015). Does Caring for a Spouse With Dementia Accelerate Cognitive Decline? Findings From the Health and Retirement Study. *The Gerontologist*, 57(2), 319–328. https://doi.org/10.1093/geront/gnv148

Dawood S. (2016). Caregiver Burden, Quality of Life and Vulnerability Towards Psychopathology in Caregivers of Patients with Dementia/Alzheimer's Disease. *Journal of College Physicians and Surgeons of Pakistan*, 26(11), 892-895. http://dx.doi.org/ 2471

Derrogatis, L. (1993). BSI Brief Symptom Inventory: Administration, Scoring, and Procedure Manual (4th Ed.). Minneapolis, MN: National Computer Systems

DGS (Health General Department - Guideline 53/2011) (2011). *Therapeutic Approach to Cognitive Disorders*. Portugal, Ministry of Health, 1-4

Endermann, M. (2005). The Brief Symptom Inventory (BSI) as a screening tool for psychological disorders in patients with epilepsy and mild intellectual disabilities in

residential care. *Epilepsy & Behavior*, 7 (1), 85-94. https://doi.org/10.1016/j.yebeh.2005.03.018

Epstein-Lubow, G., Gaudiano, B., Darling, E., Hinckley, M., Tremont, G., Kohn, R., et al. (2012). Differences in depression severity in family caregivers of hospitalized individuals with dementia and family caregivers of outpatients with dementia. *American Journal of Geriatric Psychiatry*, 20, 815–9. http://dx.doi.org/10.1097/JGP.0b013e318235b62f

Feast, A., Moniz-Cook, E., Stoner, C., Charlesworth, G., & Orrell, M. (2016). A systematic review of the relationship between behavioral and psychological symptoms (BPSD) and caregiver well-being. *International Psychogeriatrics*, 28, 1761–74. http://dx.doi.org/ 10.1017/S1041610216000922

Garrett, C., Santos, F., Tracana, I., Barreto, J., Sobral, M., & Fonseca. R. Clinical evaluation of dementia (2008). *Scales and tests in dementia* [Avaliação clínica da demência. Escalas e testes na demência,] Grupo de Estudos de Envelhecimento Cerebral e Demências

Gaugler, J.E., Mittelman, M.S., Hepburn, K., & Newcomer, R. (2010). Clinically significant changes in burden and depression among dementia caregivers following nursing home admission. *BMC Medicine*, 8, 85. https://doi.org/10.1186/1741-7015-8-85

GEECD - *Study Group on Brain Aging and Dementias* [Grupo de Estudos de Envelhecimento Cerebral e Demências (2008). Scales and Tests in Dementia [Escalas e Testes na Demência]. In: Mendonça A, Guerreiro M (Eds). Edição do Grupo de Estudos de Envelhecimento Cerebral e Demências.

Gillespie, R., Mullan, J., & Harrison, L. (2014). Managing medications: The role of informal caregivers of older adults and people living with dementia: A review of the literature. *Journal of Clinical Nursing*, 23, 3296–308. http://dx.doi.org/ 10.1111/jocn.12519

Gitlin, L., & Hodgson, N. (2016). Who Should Assess the Needs of and Care for a Dementia Patient's Caregiver? *AMA Journal of Ethics*, 18(12), 1171-1181. https://doi.org/10.1001/journalofethics.2016.18.12

Goren, A., Montgomery, W., Kahle-Wrobleski, K., Nakamura, T. & Ueda, K. (2016). Impact of caring for persons with Alzheimer's disease or dementia on caregivers' health outcomes: Findings from a community based survey in Japan. *BMC Geriatrics*, 16, 22. http://dx.doi.org/ 10.1186/s12877-016-0298-y

Hanson, E., Hellstrom, A., Sandvide, A., Jackson, G. A, MacRae, R., Waugh, A. el al , (2016). The extended palliative phase of dementia - An integrative literature review, *Dementia*, 1 - 27. https://doi.org/10.1177/1471301216659797

Harris, D. (2006). Forget me not: palliative care for people with dementia. *Postgraduate Medicine Journal*, 83, 362-366. https://doi.org/10.1136/pgmj.2006.052936

Holmerová, I., Waugh, A., MacRae, R., Veprková, R., Sandvide, A., Hanson, E. et al (2016). *Best Practice Statement*. EU, Erasmus Plus, Palliare Project.

Hughes, C., Berg, L., Danziger, W., Coben, L., & Martin, R. (1982). A new clinical scale for the staging of dementia. *British Journal of Psychiatry*, 140, 566 -572. PMID: 7104545

Irwin, S., Mausbach, B., Koo, D., Fairman, N., Roepke-Buehler, S., Chattillion, E., & Grant, I. (2013). Association between hospice care and psychological outcomes in Alzheimer's spousal caregivers. *Journal of Palliative Medicine*. 16 (11), 1450-1454. https://doi.org/10.1089/jpm.2013.0130

Jones, L., Candy, B., Davis, S., Elliott, M., Gola, A., Harrington, J., & Sampson, E. (2016). Development of a model for integrated care at the end of life in advanced dementia: A whole systems UK-wide approach. *Palliative Medicine*, 30 (3), 279-95. http://dx.doi.org/10.1177/0269216315605447

Kasper, J., Freedman, V., Spillman, B., & Wolff, J. (2015). The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs*, 34, 1642–9. http://dx.doi.org/10.1377/hlthaff.2015.0536

Liu, W., & Gallagher-Thompson, D. (2009). Impact of dementia caregiving: Risks, strains, and growth. In: Qualls SH, Zarit SH (Eds). *Aging families and caregiving*. Hoboken, N.J.: John Wiley & Sons, Inc., 85–112

Martins, D., Carvalho I., Cordeiro N. & Pinheira V. (2012). *Validation of the Edmonton Frail Scale (EFS) to the Portuguese reality* [Contributo para a validação da Escala de Fragilidade de Edmonton (EFS) para a realidade portuguesa]. Castelo Branco: International Portuguese-Spanish Congress (Communication)

Mausbach, B., Chattillion, E., Ho, J., Flynn, L., Tiznado, D., von Kanel, R., et al. (2014). Why does placement of persons with Alzheimer's disease into long-term care improve caregivers' well-being? Examination of psychological mediators. *Psychology and Aging*, 29, 776–86. http://dx.doi.org/ 10.1037/a0037626

Monin, J., Schulz, R., & Feeney, B. (2015). Compassionate love in individuals with Alzheimer's disease and their spousal caregivers: Associations with caregivers' psychological health. *The Gerontologist*. 55, 981–9. http://dx.doi.org/ 10.1093/geront/gnu001

Morris, J. (1993). The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology*, 43, 2412-4. https://doi.org/10.1037/a0021292.

Muders, P., Zahrt-Omar, C., Bussmann, S., Haberstroh, J., & Weber M. (2015). Support for families of patients dying with dementia: A qualitative analysis of bereaved family members' experiences and suggestions. *Palliative Supportive Care*, 435-442. https://doi.org/10.1017/S1478951513001107

Murray, T., Sachs, G., Stocking, C., & Shega, J. (2012). The symptom experience of community-dwelling persons with dementia: self and caregiver report and comparison with standardized symptom assessment measures. *American Journal of Geriatric Psychiatry*, 20 (4), 298-305. https://doi.org/10.1097/JGP.0b013e318235b758.

O'Bryant, S., Lacritz, L., Hall, J., Waring, S., Chan, W., Khodr, Z. ...& Cullum, C. (2010). Validation of the new interpretive guidelines for the Clinical Dementia Rating. *Archives of Neurology*, 67(6), 746-9. http://dx.doi.org/ 10.1001/archneurol.2010.115.

Ornstein, K., & Gaugler, J.E. (2012). The problem with "problem behaviors": A systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient-caregiver dyad. *International Psychogeriatrics*, 24, 1536–52. http://dx.doi.org/ 10.1017/S1041610212000737

Payton A (2009). Mental health, mental illness, and psychological distress: same continuum or distinct phenomena? *Journal of Health and Social Behaviourism*, 50(2):213-27.

Penders, Y., Albers, G., Deliens, V., Stichele, R., & Van den Block, L. (2015). Awareness of dementia by family carers of nursing home residents dying with dementia: a post-death study. *Palliative Medicine*, 29 (1), 38-4. : https://doi.org/10.1177/0269216314542261

Peng, H., & Chang, Y. (2013). Sleep Disturbance in Family Caregivers of Individuals With Dementia: A Review of the Literature. *Perspectives of Psychiatric Care*, 49(2), 135-46. https://doi.org/10.1111/ppc.12005.

Pereda, N., Forns, M., & Peró, M. (2007). Dimensional structure of the Brief Symptom Inventory with Spanish college students. *Psicothema*, 19 (4), 634-639. ISSN Paper Edition: 0214-9915

Peterson, R. (1994). A meta-analysis of Cronbach's coefficient alpha. *Journal of Consumer Research*, 21, 381-391. https://doi.org/10.1086/209405

Pialoux, T., Goyard, J., & Herme, R. (2013). When frailty should mean palliative care. *Journal of Nursing Education and Practice*, 3 (7), 75-84. https://doi.org/10.5430/jnep.v3n7p75

Piersma, H., Reaume, W., & Boes, J. (1994). The Brief Symptom Inventory (BSI) as an outcome measure for adult psychiatric inpatients. *Journal of Clinical Psychology*, 50(4), 555-63. PMID: 7983203

Prorok, J., Horgan, S., & Seitz, D. (2013). Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies. *Canadian Medical Association Journal*, 185(14), 669-80. https://doi.org/10.1503/cmaj.121795

Rattinger, G., Fauth, E., Behrens, S., Sanders, C., Schwartz, S., Norton, M., et al. (2016). Closer caregiver and care-recipient relationships predict lower informal costs of dementia care: The Cache County Dementia Progression Study. *Alzheimer & Dementia*, 2, 917–24. http://dx.doi.org/ 10.1016/j.jalz.2016.03.008

Rattinger, G., Schwartz, S., Mullins, C.D., Corcoran, C., Zuckerman, I., Sanders, C., et al. (2015). Dementia severity and the longitudinal costs of informal care in the Cache County population. *Alzheimer & Dementia*, 11, 946–54. http://dx.doi.org/10.1016/j.jalz.2014.11.004

Rolfson, D., Majumdar, S., Tsuyuki, R., Tahir, A., & Rockwood, K. (2006). Validity and reliability of the Edmonton Frail Scale. *Age and Ageing*, 35, 526–9. http://dx.doi.org/ 10.1093/ageing/afl041

Roth, D., Dilworth-Anderson, P., Huang, J., Gross, A. & Gitlin, L. (2015). Positive aspects of family caregiving for dementia: Differential item functioning by race. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 70, 813–9. https://doi.org/10.1093/geronb/gbv034

Rubin, R., & White-Means, S. (2009). Informal caregiving: Dilemmas of sandwiched caregivers . *Journal of Family and Economic Issues*, 30, 252–67. http://dx.doi.org/10.1007/s10834-009-9155-x

Sadak, T., Foster, Z., Don, S., Ishado, E., Zaslavsky, O., & Borson, S. (2017). Potentially preventable hospitalizations in dementia: family caregiver experiences. *International Psychogeriatrics*, 29(7), 1201-1211. https://doi.org/10.1017/S1041610217000217

Sallim, A., Sayampanathan, A,. Cuttilan, A., & Chun-Man, Ho, (2015). Prevalence of mental health disorders among caregivers of patients with Alzheimer disease. *Journal of the American Medical Directors Association*, 16, 1034–41. http://dx.doi.org/ 10.1016/j.jamda.2015.09.007

Sequeira, C. (2010). Adaptation and validation of Zarit Burden Interview Scale. *Revista Referência*, 2(12), 9-16. Disponible in [http://www.index-f.com/referencia/2010/12-0916.php]

Sorrell, J., & Cangelosi, P. (2009). Respecting vulnerability: Informed consent in persons with Alzheimer's disease. Southern Online *Journal of Nursing Research*, 9 (4), 1-7

Soto-Rubio, A., Pérez-Marín,M., & Barreto; P. (2017). Frail elderly with and without cognitive impairment at the end of life: Their emotional state and the wellbeing of their family caregivers. *Archives of Gerontology and Geriatrics*, 73, 113-119. http://dx.doi.org/10.1016/j.archger.2017.07.024

Terum, T., Andersen, J., Rongve, A., Aarsland, D., Svendsboe, E., & Testad, I. (2017). The relationship of specific items on the Neuropsychiatric Inventory to caregiver burden in dementia: a systematic review. *International Journal of Geriatric Psychiatry*, 32(7), 703-717. https://doi.org/10.1002/gps.4704

Thompson, G., & Roger, K. (2014). Understanding the needs of family caregivers of older adults dying with dementia. *Palliative and Supportive Care*, 12 (3), 223-231. https://doi.org/10.1017/S1478951513000461

Tolson, D., Fleming, A., Hanson, E., Abreu, W., Lillo Crespo, M., Macrae, R., Jackson,.G., Touzery, S., Routasola, P., & Holmerova, I. (2014). Achieving Prudent Dementia Care (Palliare): An International Policy and Practice Imperative. *International Journal of Integrated Care*, 16 (4), 18, 1–11. http://dx.doi.org/10.5334/ijic.2497.

Tolson, D., Holmerova, I., Macrae, R., Waugh, A., Touzery, S., Abreu et al (2017). Improving Advanced Dementia Care: An Interprofessional Palliare Learning Framework, *Journal of the American Medical Directors Association*, 1 (1), 2 - 8. https://doi.org/10.1016/j.jamda.2017.03.014

Vaingankar, J., Chong, S., Abdin, E., Picco, L., Shafie, S., Seow, E., et al. (2016). Psychiatric morbidity and its correlates among informal caregivers of older adults. *Comprehensive Psychiatry*, 68, 178–85. http://dx.doi.org/ 10.1016/j.comppsych.2016.04.017

Van der Steen, J., Radbruch, L., Hertogh, C., de Boer, M., Hughes, J., Larkin, P. et al. (2014). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine*, 28 (3). https://doi.org/10.1177/0269216313493685

Vitaliano, P., Ustundag, O., & Borson, S. (2016). Objective and subjective cognitive problems among caregivers and matched non-caregivers. *The Gerontologist*, 57(4):637-647. http://dx.doi.org/ 10.1093/geront/gnv690

Whitehouse, P. (2000). Ethical issues in dementia. *Dialogues Clinical Neuroscience*, 2 (2), 162–167. PMCID: PMC3181593

Wieland, j., Wardenaar, K., Fontein1, E., & Zitman. E. (2012). Utility of the Brief Symptom Inventory (BSI) in psychiatric outpatients with intellectual disabilities. *Journal of*

Intellectual Disability Research, 56 (9), 843–853. http://dx.doi.org/10.1111/j.1365-2788.2011.01440.x

Williams, M., Roe, C., & Morris, J. (2009). Stability of the Clinical Dementia Rating, 1979-2007. *Archives of Neurology*, 66(6), 773-7. http://dx.doi.org/ 10.1001/archneurol.2009.69.

Wolff, J., Spillman, B., Freedman, V., & Kasper, J. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine*, 176, 372–9. http://dx.doi.org/ 10.1001/jamainternmed.2015.7664

World Health Organization (2012.) *Dementia: A Public Health Priority*. Genève, WHO

World Health Organization (2015). *The epidemiology and impact of dementia current state and future trends*. Genève, WHO

WHO (2017). *Dementia* - http://www.who.int/mediacentre/factsheets/fs362/en/ (Fact sheet) (Consulted in July 25 2017)

Zarit, S. (2012). Positive aspects of caregiving: more than looking on the bright side. *Aging and Mental Health*, 16, 673–4. http://dx.doi.org/ 10.1080/13607863.2012.692768

Zarit, S., Reever, K., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, 20(6), 649–55. http://dx.doi.org/10.1093/geront/20.6.649

Zhu, C., Scarmeas, N., Ornstein, K., Albert, M., Brandt, J., Blacker, D., et al. (2015). Health-care use and cost in dementia caregivers: longitudinal results from the Predictors Caregiver Study. *Alzheimer & Dementias*, 11(4), 444–54. http://dx.doi.org/10.1016/j.jalz.2013.12.018

Zunino, R., Nassar, S., Goncalves, L., Martins, M., & Costa, M. (2011). The Family Dynamics of Elder Elderly in the Context of Porto, Portugal, *Revista Latino-americana de Enfermagem*, 19 (3), 458 - 466. http://dx.doi.org/10.1590/S0104-116920110003000